

The Mesothelioma Applied Research Foundation

Our mission is to eradicate mesothelioma as a life-ending disease.



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SUMMER 2004

BREATH OF HOPE

Message from the Executive Director

With great excitement we bring you this, the first ever issue of MARF's Newsletter – Breath Of Hope. This project has been in the works for some time and will now be a regular part of MARF's communication with those of you who generously give of yourselves and your resources to advance MARF's mission of eradicating mesothelioma as a life ending disease. Each newsletter will focus on five areas: advancement of research, treatment and care, advocacy, volunteer programs and support, and fundraising. There is a lot to say. Since 1999 MARF has grown dramatically, building from the passion, vision and generosity of our founder, Roger Worthington; the excellence and dedication of our Board of Directors and Science Advisory Board; core financial support; and most importantly, a large network of patients, family members and others who care deeply about our mission. Our executive office – originally just me

working from my home in Santa Barbara – now includes Rob Grayson, Associate Director for Volunteers and Programs, and Ray Rengo, Project Coordinator. As a team we are dedicated to eradicating mesothelioma through research, patient/family member education and support, and advocacy and awareness. We are making a major impact on the once overlooked and underserved mesothelioma crisis. I am certain the increased communication facilitated by this newsletter will help move us all one step closer to our goal. Thank you for your continued support and thank you for being a part of the MARF family!

A handwritten signature in black ink that reads "Christopher E. Hahn".

A Tribute to Our Heroes

Our loved ones lost to mesothelioma and those living with the disease deserve to be remembered and honored. This is also an important part of raising the much needed national awareness. We have therefore created a place on our website to publicly pay tribute to these heroes. From our homepage you can access this new "Tributes" page. In the future this site will include space for a photograph and a statement or remembrance of our loved ones, and it will become a powerful testament to the lives of the heroes who served and built our

country, cared for their families, and battled this disease courageously. We will soon invite family members of our "Tribute" heroes to submit photos and statements to be used on the site. If you have a loved one living with mesothelioma or have lost a loved one to this disease, we hope you will join us in building a site that truly honors these individuals. For more information, please contact our office or watch your mail box for further updates.

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TOGETHER
WE CAN MAKE
A DIFFERENCE

BELIEVE
IN A CURE

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Chapter Chatter - MARF's Volunteer Network

With the introduction of MARF's first newsletter it is exciting to include a section that focuses on what's going on within the MARF Volunteer Network. In the big picture – the MVN has grown from one chapter in Pittsburgh, PA to a network of over 60 volunteers working individually and in 6 different chapters, with more chapters forming. And to say that these chapters have hit the ground running would be an understatement. In Duluth, Minnesota chapter leader Jodi Helmer organized their first fundraiser complete with music, food, fun, and lots of raffle prizes. They sold over 1,000 tickets to the event and raised \$16,000! It was such a success that they are already planning for next year. Way to go Jodi! Just across the pond in Michigan, volunteers

Sandy O'Neil, Kathi Curtis, and Elana Lanzetta hosted a bowling fundraiser in memory of their father Les Lanzetta. There was food, silent auction, prizes, and of course bowling. They raised over \$9,000! Last February a group of women who had lost a dear friend, Michal Evans Flach, banded together to raise money in her memory. Organized by Betsy Brown of Hilton Head, North Carolina, these 12 women wrote to all the people they knew and who also knew their friend Michal, asking them to support mesothelioma research with a gift to MARF. They sent out nearly 600 letters. During the course of the next 6 weeks MARF received over \$25,000 from the Friends of Michal fundraiser. Everyday, volunteers make a difference!

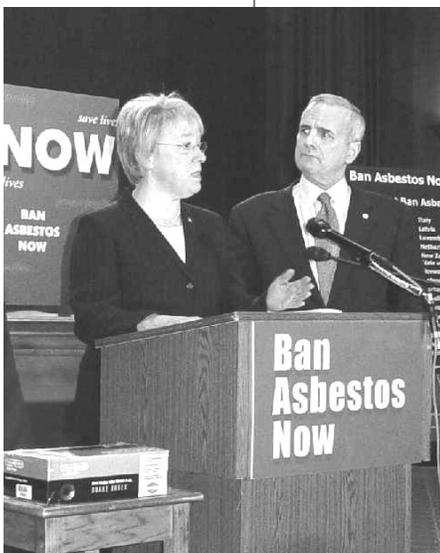
To find out how
you can get
involved or to
become a
volunteer...
visit us on
the web at
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MARF Backs Sen. Murray's Ban Asbestos Bill

On March 24, MARF Executive Director Chris Hahn, along with dozens of MARF patients and family members from around the country, met in Washington D.C. for a press conference to support Senator Patty Murray's proposed Ban Asbestos in America Act (S.1115). This bill addresses our nation's asbestos problem right at its heart – asbestos is still causing suffering and must be banned; and what those who are already sick and those who will get sick in the

future need more than anything is research to develop effective treatments and hope for a cure. Senator Murray, Senator Mark Dayton and Senator Harry Reid all spoke powerfully, committing themselves to the fight to enact the bill as law. MARF Science Advisory Board Chairman Dr. Harvey Pass demonstrated that, after decades of neglect, the time is right for our hope that mesothelioma can be medically beaten, if we allocate the resources. MARF also brought to the conference recently diagnosed mesothelioma patient Dr. Bret Williams. "As a doctor, a cancer patient, and a husband and father," Dr. Williams challenged our government to stand against asbestos and invest in a cure. The effects of this event have been powerful. The fact that Senator Reid, the number two ranking Democrat in the Senate, acknowledged the suffering of mesothelioma victims and vowed to fight for Senator Murray's bill is a huge step forward. A number of other Senators have now joined as cosponsors as well. Following the press conference, the need for research funding as the most essential way to address mesothelioma victims' suffering began to be raised as never before in the political debate on asbestos litigation and in the media. Senator Murray's call to ban asbestos and fund mesothelioma research is beginning to receive the important attention it deserves. At the press conference and in a later speech on the Senate floor, Senator Murray thanked MARF and several of our doctors and representatives for our work in support of her bill.

Senator Patty Murray, with the support of Senators Mark Dayton and Harry Reid (not shown), calls for banning asbestos and federal funding of mesothelioma research.



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Focus on Research - MARF's Research Program Explained

MARF began its mesothelioma research program in 2000 based on the belief that mesothelioma's label as an untreatable, incurable disease was wrong. True, the tumor had resisted virtually all standard chemotherapies; but these drugs were all developed for other cancers. For decades, there had been no independent funding for mesothelioma and almost no federal funding. Who could say mesothelioma was untreatable, since no full-scale effort to develop effective treatments had ever been made? Emerging signs of hope now justify MARF's belief that successful treatments for mesothelioma will be developed. As mesothelioma research funding has increased, we have seen that:

- ◆ Researchers, from young investigators making career choices to large pharmaceutical companies, are realizing that mesothelioma is a fertile ground for study and development of new types of therapies;
- ◆ Aided by new technologies, including gene and protein profiling, these researchers are now learning how this complicated tumor grows, invades, and even starts;
- ◆ This is leading to progress in finding the disease earlier, exposing its Achilles' heel, and developing new treatments designed to destroy the mesothelioma tumor specifically;
- ◆ The first FDA approved drug developed specifically for mesothelioma, Alimta (approved February 5, 2004), does indeed shrink mesothelioma tumor 2-3 times better than the old therapies.

MARF's competitive research grants program is designed specifically for mesothelioma, to stimulate progress toward a cure as effectively and quickly as possible. Grants are for \$100,000, over two years. This allows rapid development of results and enables MARF to diversify its investment in research. At this level the grants serve as seed-money, tending to attract ambitious studies based on new

concepts. This type of innovative research is critically needed now in mesothelioma, but because this research is highly experimental and relates to a "low-incidence" disease, it is not likely to obtain funding through the National Cancer Institute or other sources. However, if the project can show success through MARF's funding, then it likely will attract greater funding, and MARF's dollars are multiplied. Selection of the projects for funding is based on the prestigious National Cancer Institute peer review model, where scientific experts in the particular field evaluate the merits of what gets funded. MARF is able to accomplish high-level, rigorous peer review through its Science Advisory Board, elite mesothelioma experts from across the country. A diverse panel of these experts, each of whom must be unassociated with any of the applicants, rigorously reviews the applications and scores them on our established set of criteria. The reviewers' scores are then cumulated, and the highest ranking applications receive the grants. This system ensures that the most meritorious studies are the ones which obtain funding. And because it creates a level playing field and equal opportunity for all, judged only on the merit of the proposed study, it stimulates scientific exploration and development of novel ideas, and attracts new researchers to the field. In addition to this system, in which the projects are initiated by the researchers, MARF also awards two other types of research funding. Sometimes donors may be grateful to a particular doctor and wish to support that doctor's research. Or a donor might be motivated by geographic concerns. In appropriate circumstances, MARF therefore accepts gifts designated to particular research projects. MARF from time to time also initiates its own special research projects. When there is an



Mesothelioma tumor specimens obtained during surgery are preserved and used for further research.

Last year
MARF awarded
\$500,000
to meet the
growing research
demands.
This year we want
to do more.

YOU CAN HELP



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Our mission is to eradicate mesothelioma as a life-ending disease.

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Focus on Research, *continued*

opportunity to foster collaboration between researchers, or there is a needed, promising area of research that is not otherwise being addressed, MARF will develop and fund that specific project. To assure excellence, all of these types of MARF research funding are subjected to rigorous peer review by MARF's scientific experts. Time is precious and the financial resources for mesothelioma research are still very limited. So it is essential that experts who understand the science ensure that the funding goes to the most promising, meritorious research proposals. MARF has now built a track record of consistently supporting high quality mesothelioma treatment research. With the reputation and broad contacts we have developed, we are attracting the most qualified research proposals from around the world. For example, in 2003 we received

25 applications from highly regarded centers in the U.S., including Harvard, Duke, Sloan Kettering and Vanderbilt, and six other countries. Applicants included highly-respected mesothelioma investigators, experts from other fields beginning to apply their expertise to mesothelioma, and young investigators newly attracted to the field. From this high quality group, MARF was able to award grants to five stellar projects. MARF has now awarded over \$1.3 million in mesothelioma research funding to exceptional projects. Beginning with Breath of Hope's next issue, we will individually profile these projects, to share with you the excitement of the advance toward curing mesothelioma.